Complete Summary

TITLE

Patients' experiences: percentage of veterans who die in an inpatient VA facility (intensive care, acute care, hospice unit, nursing home care unit or community living center) for whom a Bereaved Family Survey (BFS) is completed with at least 78% of items receiving an optimal response.

SOURCE(S)

Casarett D. Bereaved family member quality survey: brief instructions. Philadelphia (PA): PROMISE Center, Center for Health Equity Research and Promotion; 2006 Mar. 7 p.

Measure Domain

PRIMARY MEASURE DOMAIN

Patient Experience

The validity of measures depends on how they are built. By examining the key building blocks of a measure, you can assess its validity for your purpose. For more information, visit the Measure Validity page.

SECONDARY MEASURE DOMAIN

Does not apply to this measure

Brief Abstract

DESCRIPTION

This measure, the Bereaved Family Survey (BFS), is used to assess families' (surrogates) perceptions of the care that is provided to veterans who die in an inpatient Veterans Affairs (VA) facility (intensive care, acute care, hospice unit, nursing home care unit or community living center).

RATIONALE

A growing body of research has underscored the degree to which end-of-life care in the United States needs to be improved. The challenges of end-of-life care are particularly significant in the U.S. Department of Veterans Affairs (VA) health care system because the VA provides care for an increasingly older population with multiple comorbid conditions. In FY2000, approximately 104,000 enrolled

veterans died in the U.S., and approximately 27,200 veterans died in VA facilities. At least 30% of veterans are over age 65 now, and 46% will be over 65 by 2030. Therefore, it is clear that the number of deaths in VA facilities will increase substantially as the World War II and Korean War veterans age. These demographic trends mean that, like other healthcare systems, the VA will face substantial challenges of providing care to veterans near the end of life.

The VA has addressed this challenge aggressively in the last 5 years; however, the VA had not yet developed and implemented measures of the quality of end-of-life care it provides to veterans. There are at least 3 reasons why adoption of a quality measurement tool is essential. First, it would make it possible to define and compare the quality of end-of-life care at each VA facility and to identify opportunities for improvement. Second, facilities and Veterans Integrated Service Networks (VISNs) (geographic service divisions within the VA system) would be able to monitor the effectiveness of efforts to improve care locally and nationally, and would enable monitoring of the impact of the Comprehensive End of Life Care Initiative, ensuring that expenditures are producing improvements in care. Third, it will help the VA to recognize those facilities that provide outstanding end-of-life care, so that successful processes and structures of care can be identified and disseminated throughout the VA.

PRIMARY CLINICAL COMPONENT

Quality of end-of-life care; experience/satisfaction with care

DENOMINATOR DESCRIPTION

Veterans who die in an inpatient Veterans Affairs (VA) facility (intensive care, acute care, hospice unit, nursing home care unit, or community living center) for whom a survey is completed (see the related "Denominator Inclusions/Exclusions" field in the Complete Summary)

NUMERATOR DESCRIPTION

Proportion of items that received the best possible response among completed surveys

Evidence Supporting the Measure

EVIDENCE SUPPORTING THE CRITERION OF QUALITY

- A clinical practice guideline or other peer-reviewed synthesis of the clinical evidence
- One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

NATIONAL GUIDELINE CLEARINGHOUSE LINK

- Clinical practice guidelines for quality palliative care.
- Palliative care.

Evidence Supporting Need for the Measure

NEED FOR THE MEASURE

Overall poor quality for the performance measured
Use of this measure to improve performance
Variation in quality for the performance measured

EVIDENCE SUPPORTING NEED FOR THE MEASURE

Bernabei R, Gambassi G, Lapane K, Landi F, Gatsonis C, Dunlop R, Lipsitz L, Steel K, Mor V. Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. JAMA1998 Jun 17;279(23):1877-82. PubMed

Breitbart W, McDonald MV, Rosenfeld B, Monkman ND, Passik S. Fatigue in ambulatory AIDS patients. J Pain Symptom Manage1998 Mar;15(3):159-67. PubMed

Breitbart W, McDonald MV, Rosenfeld B, Passik SD, Hewitt D, Thaler H, Portenoy RK. Pain in ambulatory AIDS patients. I: Pain characteristics and medical correlates. Pain1996 Dec;68(2-3):315-21. PubMed

Bruera E, Schmitz B, Pither J, Neumann CM, Hanson J. The frequency and correlates of dyspnea in patients with advanced cancer. J Pain Symptom Manage2000 May;19(5):357-62. PubMed

Cleeland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA, Pandya KJ. Pain and its treatment in outpatients with metastatic cancer. N Engl J Med1994 Mar 3;330(9):592-6. PubMed

Field MJ, Cassel CK, editor(s). Approaching death: improving care at the end of life. Washington (DC): National Academy Press; 1997. 437 p.

Grassi L, Indelli M, Marzola M, Maestri A, Santini A, Piva E, Boccalon M. Depressive symptoms and quality of life in home-care-assisted cancer patients. J Pain Symptom Manage1996 Nov;12(5):300-7. PubMed

Hallenbeck J. Building or expanding palliative care programs in the Department of Veterans Affairs healthcare system. [internet]. Washington (DC): Department of Veterans Affairs; [accessed 2009 Jun 09].

Hofmann JC, Wenger NS, Davis RB, Teno J, Connors AF Jr, Desbiens N, Lynn J, Phillips RS. Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment. Ann Intern Med1997 Jul 1;127(1):1-12. PubMed

Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF Jr. Perceptions by family members of the dying

experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Ann Intern Med1997 Jan 15;126(2):97-106. PubMed

Phillips RS, Wenger NS, Teno J, Oye RK, Youngner S, Califf R, Layde P, Desbiens N, Connors AF Jr, Lynn J. Choices of seriously ill patients about cardiopulmonary resuscitation: correlates and outcomes. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Am J Med1996 Feb;100(2):128-37. PubMed

Teno JM, Hakim RB, Knaus WA, Wenger NS, Phillips RS, Wu AW, Layde P, Connors AF Jr, Dawson NV, Lynn J. Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resource use. The SUPPORT Investigators. J Gen Intern Med1995 Apr;10(4):179-86. PubMed

Ventafridda V, Ripamonti C, De Conno F, Tamburini M, Cassileth BR. Symptom prevalence and control during cancer patients' last days of life. J Palliat Care1990 AUTUMN;6(3):7-11. PubMed

VetPop 2001. Vol 2002. Washington (DC): Office of the Actuary Assistant Secretary for Policy & Planning, Department of Veterans Affairs; 2002.

Zhukovsky DS, Gorowski E, Hausdorff J, Napolitano B, Lesser M. Unmet analgesic needs in cancer patients. J Pain Symptom Manage1995 Feb;10(2):113-9. PubMed

State of Use of the Measure

STATE OF USE

Current routine use

CURRENT USE

Decision-making by managers about resource allocation
External oversight/Veterans Health Administration
Federal health policymaking
Internal quality improvement
Pay-for-performance
Quality of care research

Application of Measure in its Current Use

CARE SETTING

Hospitals
Long-term Care Facilities
Managed Care Plans
Rehabilitation Centers
Residential Care Facilities
Rural Health Care

PROFESSIONALS RESPONSIBLE FOR HEALTH CARE

Measure is not provider specific

LOWEST LEVEL OF HEALTH CARE DELIVERY ADDRESSED

Single Health Care Delivery Organizations

TARGET POPULATION AGE

All veterans meeting inclusion criteria are included, regardless of age

TARGET POPULATION GENDER

Either male or female

STRATIFICATION BY VULNERABLE POPULATIONS

Unspecified

Characteristics of the Primary Clinical Component

INCIDENCE/PREVALENCE

Approximately 2% of all veterans die every year. Of those, 20% are enrolled in the Veterans Affairs (VA) health system, and 5% die in VA facilities.

See also the "Rationale" field.

EVIDENCE FOR INCIDENCE/PREVALENCE

Hallenbeck J. Building or expanding palliative care programs in the Department of Veterans Affairs healthcare system. [internet]. Washington (DC): Department of Veterans Affairs; [accessed 2009 Jun 09].

National Center for Veterans Analysis and Statistics. VA Benefits & Health Care Utilization. Washington (DC): VA Office of Research and Development; 2008 Oct 27. 1 p.

VetPop 2001. Vol 2002. Washington (DC): Office of the Actuary Assistant Secretary for Policy & Planning, Department of Veterans Affairs; 2002.

ASSOCIATION WITH VULNERABLE POPULATIONS

Most of the subjects included are disabled, frail elderly, and terminally ill, and a significant percentage also qualify as either mentally ill, medically uninsured, poverty population, homeless, or urban population as well.

EVIDENCE FOR ASSOCIATION WITH VULNERABLE POPULATIONS

National Center for Veterans Analysis and Statistics. FY07 VA information pamphlet. Washington (DC): Department of Veterans Affairs, Veteran Data and Information Web site; 2008 Feb. 2 p.

National Center for Veterans Analysis and Statistics. VA stats at a glance. Washington (DC): Department of Veterans Affairs, Veteran Data and Information Web site; 2008 Oct 27. 1 p.

BURDEN OF ILLNESS

Unspecified

UTILIZATION

Unspecified

COSTS

Unspecified

Institute of Medicine National Healthcare Quality Report Categories

IOM CARE NEED

End of Life Care

IOM DOMAIN

Patient-centeredness

Data Collection for the Measure

CASE FINDING

Users of care only

DESCRIPTION OF CASE FINDING

Veterans who die in an inpatient Veterans Affairs (VA) facility (intensive care, acute care, hospice unit, nursing home care unit, or community living center) for whom a survey is completed

DENOMINATOR SAMPLING FRAME

Patients associated with provider

DENOMINATOR INCLUSIONS/EXCLUSIONS

Inclusions
Veterans who die in an inpatient Veterans Affairs (VA) facility (intensive care, acute care, hospice unit, nursing home care unit, or community living center) for whom a survey is completed*

*'Completed' surveys are defined as those with at least 10 of the 14 structured items completed (approximately 70%).

Exclusions

- Deaths within 24 hours of admission (unless the veteran had a previous hospitalization in the last month of life)
- Deaths that occur in the Emergency Department
- Deaths that occur in the operating room
- Deaths due to suicide or accidents
- Veterans for whom a family member knowledgeable about their care cannot be identified (determined by the family member's report) or contacted (no current contacts listed or no valid addresses on file)
- Absence of a working telephone available to the family member

RELATIONSHIP OF DENOMINATOR TO NUMERATOR

All cases in the denominator are equally eligible to appear in the numerator

DENOMINATOR (INDEX) EVENT

Institutionalization
Patient Characteristic

DENOMINATOR TIME WINDOW

Time window brackets index event

NUMERATOR INCLUSIONS/EXCLUSIONS

Inclusions
Proportion of items that received the best possible response among completed surveys

Exclusions
Unspecified

MEASURE RESULTS UNDER CONTROL OF HEALTH CARE PROFESSIONALS, ORGANIZATIONS AND/OR POLICYMAKERS

The measure results are somewhat or substantially under the control of the health care professionals, organizations and/or policymakers to whom the measure applies.

NUMERATOR TIME WINDOW

Encounter or point in time

DATA SOURCE

Patient survey

LEVEL OF DETERMINATION OF QUALITY

Not Individual Case

OUTCOME TYPE

Does not apply to this measure

TYPE OF HEALTH STATE

Does not apply to this measure

PRE-EXISTING INSTRUMENT USED

Bereaved Family Survey (BFS)

Computation of the Measure

SCORING

Rate

INTERPRETATION OF SCORE

Better quality is associated with a higher score

ALLOWANCE FOR PATIENT FACTORS

Analysis by subgroup (stratification on patient factors, geographic factors, etc.)

DESCRIPTION OF ALLOWANCE FOR PATIENT FACTORS

Provisions are made to conduct a subset analysis by site of death (e.g., acute care vs. long term care), diagnosis (e.g., cancer vs. non-cancer) and use of a palliative consult.

STANDARD OF COMPARISON

Internal time comparison
Prescriptive standard

PRESCRIPTIVE STANDARD

The standard used is the pooled average of surveys that comprise at least the top 10% of the total sample, representing at least the top 10% of facilities.

EVIDENCE FOR PRESCRIPTIVE STANDARD

Weissman NW, Allison JJ, Kiefe CI, Farmer RM, Weaver MT, Williams OD, Child IG, Pemberton JH, Brown KC, Baker CS. Achievable benchmarks of care: the ABCs of benchmarking. J Eval Clin Pract1999 Aug;5(3):269-81. [75 references] PubMed

Evaluation of Measure Properties

EXTENT OF MEASURE TESTING

The Bereaved Family Survey (BFS) has been developed based on interviews with over 1,000 family members, and pilot testing has included an additional 1,000 family members. The 14 closed-ended survey items were selected from among the items in the Family Assessment of Treatment at End-of-life (a Veterans Affairs [VA]-specific instrument developed with support from a VA HSRD Merit Award) based on their psychometric characteristics and homogeneity as measured by the Cronbach's alpha, psychometric characteristics, and discriminant validity. Survey data will be supplemented by medical record reviews to determine eligibility and to define key veteran characteristics (e.g., age, ethnicity, site of death). This chart abstraction tool has also been developed, refined, and tested for interrater reliability. No additional instrument development will be required.

Development of the BFS in 5 facilities has provided the following evidence of its reliability and validity.

1. Selection bias: The only independent predictor of response rate was the veteran's facility. After adjusting for facility, there were no significant differences between veterans for whom a survey was completed and all others with respect to the veteran's age, ethnicity, use of hospice, use of palliative care, site of death (e.g., acute care or Community Living Center), or relationship to his/her next of kin (e.g., spouse, child, other).
2. Familiarity of respondents with the veteran's care: 71% of respondents had contact with the veteran every day, or almost every day, in the veteran's last month of life. There was no relationship between the respondent's frequency of contact with the veteran and the respondent's rating of the veteran's care.
3. Survey psychometric characteristics: The BFS gives a continuous score (possible range 0-100), reflecting the average of 14 dichotomous items, that is approximately normally distributed (mean 57, median 60, standard deviation 25; actual range 0-100). Only 5% of surveys had a score greater than 90, indicating no ceiling effect. Cronbach's alpha for the survey was 0.81, indicating good homogeneity that is sufficient for between-group comparisons (e.g., comparisons among facilities).
4. Reliability: As is typical of surveys of bereaved family members, this survey has not undergone testing of retest reliability. However, available evidence indicates that families' perceptions of care are stable over time. That is, there is no association between the timing of the interview after the veteran's death (range: 6-10 weeks) and the respondent's rating of the care that the veteran received.

5. Validity: The most important test of the survey's usefulness is its discriminant validity. That is, its ability to distinguish among groups that should, in theory, have different scores. Pilot testing of the survey has identified the following evidence of its discriminant validity:
    A. The survey scores vary significantly among the 5 pilot sites (range: 45-67; rank sum test $p<0.001$).
    B. In pilot testing in 32 sites and 19 nursing homes, we have found similar evidence of variation (range 50-76).
    C. The use of a palliative care consult is associated with a higher score compared to usual care (mean 59 vs. 50; $p<0.001$).
    D. Death in a palliative care unit is associated with a higher score than death on an acute care ward (mean 63 vs. 51; rank sum test $p<0.001$).

EVIDENCE FOR RELIABILITY/VALIDITY TESTING

Casarett D, Pickard A, Amos Bailey F, Ritchie C, Furman C, Rosenfeld K, Shreve S, Shea JA. Important aspects of end-of-life care among veterans: implications for measurement and quality improvement. J Pain Symptom Manage2008 Feb;35(2):115-25. [42 references] PubMed

Casarett D, Pickard A, Bailey FA, Ritchie C, Furman C, Rosenfeld K, Shreve S, Chen Z, Shea JA. Do palliative consultations improve patient outcomes?. J Am Geriatr Soc2008 Apr;56(4):593-9. PubMed

Casarett D, Pickard A, Bailey FA, Ritchie CS, Furman CD, Rosenfeld K, Shreve S, Shea J. A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life. J Palliat Med2008 Jan-Feb;11(1):68-75. [21 references] PubMed

Finlay E, Shreve S, Casarett D. Nationwide veterans affairs quality measure for cancer: the family assessment of treatment at end of life. J Clin Oncol2008 Aug 10;26(23):3838-44. [61 references] PubMed

Identifying Information

ORIGINAL TITLE

Bereaved Family Survey (B.F.S).

MEASURE COLLECTION

Bereaved Family Survey (BFS)

DEVELOPER

Casarett, David, MD, MA; VA Medical Center

FUNDING SOURCE(S)

Unspecified

COMPOSITION OF THE GROUP THAT DEVELOPED THE MEASURE

Unspecified

FINANCIAL DISCLOSURES/OTHER POTENTIAL CONFLICTS OF INTEREST

Unspecified

ADAPTATION

Measure was adapted from another source.

PARENT MEASURE

The Family Assessment of Treatment at End-of-life (F.A.T.E.) survey (developed by David Casarett, VA Medical Centers)

RELEASE DATE

2006 Mar

REVISION DATE

2008 Aug

MEASURE STATUS

This is the current release of the measure.

SOURCE(S)

Casarett D. Bereaved family member quality survey: brief instructions. Philadelphia (PA): PROMISE Center, Center for Health Equity Research and Promotion; 2006 Mar. 7 p.

MEASURE AVAILABILITY

The individual measure, "The Bereaved Family Survey," is available in the "Bereaved Family Member Quality Survey: Brief Instructions." The document is available in Portable Document Format (PDF) from the Caring for Veterans Web site.

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NQMC STATUS

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